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**PATIENT VERSUS PHYSICIAN PERCEPTIONS OF PROGNOSIS
AND END-OF-LIFE OUTCOMES IN ACUTE LEUKEMIA**

A Thesis Submitted to the Yale School of Medicine
In Partial Fulfillment of the Requirements
For the Degree of Doctor of Medicine

By

Sophia Shimer

2019

ABSTRACT

PATIENT VERSUS PHYSICIAN PERCEPTIONS OF PROGNOSIS AND END-OF-LIFE OUTCOMES IN ACUTE LEUKEMIA.

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Background: Acute leukemia poses unique challenges for prognostication. In many cases, cure is possible but unlikely and treatment is risky. Little is known about how patients perceive their prognosis. The purpose of this study was to assess prognostic understanding and end-of-life outcomes in patients with acute leukemia.

Methods: In this observational study, we surveyed patients admitted with acute leukemia and their treating hematologists. We elicited patient preferences for prognostic information and asked whether goals of care discussions had occurred. We then compared patient vs physician perceptions of treatment goals, chance of cure, expected survival, and chance that treatment would lessen suffering. Patient-physician concordance was assessed with kappa statistics. After a minimum follow-up of 1 year, we compared perceptions of prognosis to actual survival outcomes. Finally, we measured healthcare utilization at the end of life.

Results: We enrolled 76.6% (105/137) of eligible patients. We restricted our analysis to the 90 patient-physician dyads in which both parties completed a survey. Although

83.5% of patients wanted to be told their prognosis, only 56.8% recalled their physician disclosing treatment response rates. Most patients (82.2%) and physicians (78.9%) shared a goal of cure. However, they differed significantly in their perceptions of the chance of cure. Both non-relapsed and relapsed patients were more likely than their physicians to report a > 80% chance of cure (57.9% vs 5.2% for non-relapsed, $p < 0.001$; 38.7% vs 0.0% for relapsed, $p < 0.001$). Among those willing to estimate survival time, 75.7% of patients vs 28.4% of physicians estimated > 5 years ($p < 0.001$). Patients were also more likely to report a > 80% chance that treatment would lessen suffering (50.6% vs 21.6%, $p < 0.001$). Patient-physician concordance was poor for both chance of cure ($\kappa = 0.05$) and chance of lessening suffering ($\kappa = 0.02$). When prognostic perceptions were compared to actual survival outcomes, 54.1% of patients and 33.8% of physicians overestimated survival. The analysis of healthcare utilization at the end of life revealed high rates of in-hospital death (50.0%); hospitalization (93.8%) and ICU admission (54.2%) within 30 days of death; and hospice enrollment within 7 days of death (37.5%).

Conclusions: Most patients overestimate their prognosis compared to their hematologist's assessment and actual survival outcomes. This finding is significant because, while optimism can help with coping, there is also a risk of unrealistic expectations influencing treatment decisions and patterns of care.

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TABLE OF CONTENTS

Introduction	1
Statement of Purpose	4
Methods	5
Results	10
Discussion	20
References	26
Appendix (Surveys)	30

INTRODUCTION

Most patients with cancer want to know their prognosis and participate actively in decision-making regarding their care.¹⁻³ The American Society of Clinical Oncology has issued consensus guidelines recommending that oncologists broach discussions about prognosis and goals of care earlier in the course of illness, not just at the end of life.^{4,5} Despite the growing call from both patients and oncologists for improved communication about prognosis, many patients hold inaccurate—and usually overly optimistic—perceptions of their prognosis. Previous research has shown that advanced cancer patients overestimate their likelihood of cure and long-term survival, misunderstand treatment intent to be curative when it is palliative, and do not acknowledge the terminal nature of their illness.^{1,6-9}

Most of the previous research on prognostic understanding was carried out in solid tumor populations.^{1,6-9} There is comparatively little data for hematologic malignancies. A few small studies have found that patients undergoing hematopoietic stem cell transplant overestimate their prognosis.¹⁰⁻¹³ El-Jawahri et al. found that 77.6% of transplant recipients overestimated chance of cure compared to their oncologist's assessment. This was despite a reported desire for prognostic information: 88.9% of patients said it was "extremely" or "very" important to learn about their prognosis, and 74.4% wanted "as much information as possible" about their prognosis.¹⁰ Grulke et al. reported that transplant recipients' prognostic estimates correlated with their psychological symptom burden, but not with objective disease- or treatment-related

variables.¹¹ More recently, El-Jawahri et al. conducted another study in older adults with acute myeloid leukemia (AML), finding that these patients overestimated both their likelihood of cure and the risk of treatment-related mortality.¹⁴ However, prognostic understanding in the acute leukemia population remains insufficiently studied.

Acute leukemias differ from solid tumors in key ways that make researching patient and physician understanding of prognosis challenging. First, there is a difference in curability: whereas advanced solid tumors are usually unambiguously incurable, in acute leukemia there is often a real possibility of cure that must be balanced against a high risk of complications.¹⁵ Second, there is a difference in illness trajectory: whereas solid tumors usually have a gradual onset and progress linearly, acute leukemias often present suddenly and follow an unpredictable course marked by intermittent periods of acute exacerbation and intensive treatments.¹⁶⁻¹⁸ A patient's condition can deteriorate suddenly and dramatically due to infection or hemorrhage, contributing to uncertainty in prognostication and timing of goals of care discussions.¹⁷

Why does prognostic understanding matter? Evidence is accumulating that prognostic misperceptions can influence treatment preferences and ultimately patterns of care. In a large cohort of patients with metastatic solid tumors, Weeks et al. demonstrated that overestimation of survival was associated with a preference for, and ultimately receipt of, more aggressive treatment.¹⁹ In the Coping with Cancer study, Enzinger et al. found

that patients who overestimated their survival were less likely to complete advance care planning such as do-not-resuscitate orders and living wills.¹

Little is known about the link between prognostic understanding and patterns of care in hematologic malignancies. In a large national survey in which hematologic oncologists were asked to identify barriers to providing quality end-of-life care for patients with blood cancers, the top reported barrier was unrealistic patient expectations.²⁰ This topic merits further investigation because hematologic malignancy patients have especially high rates of healthcare utilization and aggressive treatment at the end of life. Compared to their counterparts with solid tumors, patients with hematologic malignancies are more than twice as likely to die in the hospital and more likely to undergo hospitalization, ICU admission, and chemotherapy within 30 days of death.^{21,22} They are less likely to receive palliative care or hospice services, and when they do enroll in hospice it is often just days before death; this is particularly true for patients with leukemia.²³⁻²⁵

Here, we report results of an observational study examining prognostic understanding and end-of-life outcomes in acute leukemia. Our study differs from previous work in the hematologic malignancy population in four key ways. First, we include patients at all stages of the acute leukemia disease trajectory (including new diagnosis, remission, and relapsed/refractory disease). Previous studies focused more narrowly on either newly diagnosed patients or those undergoing transplant.^{10-14,26} Recently, Kayastha et al.

examined the impact of relapse status on patient-reported outcomes such as quality of life and distress, but they did not assess prognostic understanding.²⁷ Further research is needed to more completely capture how prognostic understanding varies at different stages of illness, for example after relapse.

Second, we evaluate the various components of prognostic understanding in richer detail. Experts in patient-physician communication have identified 5 distinct elements of prognostic understanding: current state of disease, life expectancy, curability, decline trajectory, and available treatment options.²⁸ Our study recognizes this multidimensionality by asking not only about chance of cure but also about other elements that are less commonly studied, such as chance that treatment will reduce suffering. Third, we compare patient perceptions of prognosis to both physician opinions and actual survival outcomes. Finally, we assess healthcare utilization at the end of life to explore the link between prognostic perceptions and patterns of care.

STATEMENT OF PURPOSE

The purpose of this observational study was to assess how well patients with acute leukemia at Yale-New Haven Hospital understand their prognosis by comparing patients' perceptions to their physicians' opinions and to actual end-of-life outcomes.

Specific aims

Aim 1: To describe patient and physician (treating hematologist) perceptions of prognosis and goals of care.

Aim 2: To measure patient-physician concordance regarding prognosis and goals of care.

Aim 3: To identify patient demographic and clinical factors associated with prognostic understanding.

Aim 4: To compare perceptions of prognosis to actual survival outcomes.

Aim 5: To assess healthcare utilization at the end of life.

Hypothesis

Our hypothesis was that patient-physician concordance regarding prognosis would be poor, and that patients would be more optimistic than their physicians.

METHODS

Participants

Patients eligible for this study were adults with acute leukemia (including acute myeloid leukemia and acute lymphoblastic leukemia) admitted to Smilow Cancer Hospital at Yale-New Haven, the clinical arm of the Yale Cancer Center. Exclusion criteria included not speaking English, serious cognitive impairment, and inability to communicate verbally with researchers.

Study design and procedures

This study was approved by the Yale Institutional Review Board. We identified potentially eligible patients by screening the inpatient hematologic malignancy service census. Consecutively eligible patients were invited to participate and provided written informed consent. Enrollment occurred between August 2015 and November 2017.

Enrolled patients completed a survey (**Appendix 1**) administered in-person by a researcher. For newly diagnosed patients, we waited at least 1 week after the date of diagnosis to administer the survey in order to allow time for cytogenetic testing and discussions about prognosis with a hematologist. Then, we asked each patient's treating hematologist to complete a short survey (**Appendix 2**) assessing the individual patient's prognosis and goals of care, using a subset of the items on the patient survey. We conducted an initial medical record review at the time of enrollment to abstract clinical factors. Finally, in December 2018, after a minimum of 1 year of follow-up, we conducted another medical record review to assess survival outcomes and healthcare utilization at the end of life.

Measures

Perceptions of prognosis and goals of care. Several items assessing prognostic perceptions were adapted from the Coping with Cancer study, a large, multisite, prospective study of psychosocial factors in patients with advanced solid tumors.^{1,29}

We asked patients whether they would want to be told their prognosis and elicited their preferences for involvement in treatment decision-making. We also asked whether they recalled their physician discussing expected survival time, treatment response rates, or end-of-life preferences.

We asked both patients and their physicians to complete the following 6 survey items, so that patient vs physician responses could be compared. 1) We asked participants to rate *current health status* as “relatively healthy,” “seriously ill,” or “terminally ill.” 2) We asked whether the *goal of current treatment* was “cure,” “extend life,” or “lessen suffering.” 3) *Likelihood of cure*, 4) *likelihood of extending life*, and 5) *likelihood of lessening suffering* were each rated on a 5-point scale (0-20%, 21-40%, 41-60%, 61-80%, and 81-100%). 6) Finally, we asked participants to estimate *survival time*, with options ranging from months to years.

Demographic factors. Patients reported age, sex, race, ethnicity, marital status, income, education, religion, and level of religiosity. Health insurance type was obtained from medical records.

Clinical factors. Type of leukemia, relapse status, and transplant status were identified by medical record review. Health-related quality of life was assessed using the Functional Assessment of Cancer Therapy—Leukemia (FACT-Leu) Version 4

instrument.³⁰ We also assessed Eastern Cooperative Oncology Group (ECOG) performance status for all patients.³¹

Survival outcomes and healthcare utilization at the end of life. At the end of the follow-up period, survival outcomes were ascertained from medical records. Overall survival was measured from the time of enrollment to death or censoring. For patients who had died, we also obtained information on place of death, hospice enrollment, receipt of palliative care consultation, hospitalization within 30 days of death, ICU admission within 30 days of death, receipt of chemotherapy or targeted therapy within 14 days of death, CPR or intubation within 30 days of death, and transfusion of red blood cells or platelets within 7 days of death. We chose these particular outcomes because they have previously been identified as standard quality measures for end-of-life care in the hematologic malignancy population.²⁰

Statistical analysis

For the purpose of sample size calculation, we chose a primary outcome of patient-physician discordance regarding likelihood of cure. We calculated a minimum sample size of 76 patients to have 80% power to detect a >1 point difference on the 5-point likelihood-of-cure scale, using a 5% significance level. We posited that a >1 point difference was clinically relevant, as this was in line with how previous studies have defined prognostic discordance.^{10,32,33}

We calculated descriptive statistics for baseline patient characteristics, including means or medians for continuous variables and frequencies for categorical variables. For our analysis comparing patient vs physician perceptions, we used two methods. First, we reported frequency distributions of patient vs physician responses and used chi-square or Fisher's exact tests to determine whether these distributions differed significantly. Second, we quantified the level of concordance between patient and physician responses using Cohen's kappa statistics. Kappa statistics were interpreted using benchmark ranges described by Landis and Koch; kappa values < 0.20 indicate poor or slight concordance, and kappa values of 0.8 to 1.0 indicate almost perfect concordance.³⁴

We used logistic regression to explore demographic and clinical factors associated with patient-physician prognostic concordance. For these analyses, prognostic concordance was defined as patient and physician rating the likelihood of cure within 1 point of each other on the 5-point likelihood-of-cure scale.

Survival analysis was conducted using the Kaplan-Meier method and log-rank tests for significance. Analyses were performed using SAS software (version 9.4; SAS Institute Inc., Cary, NC). All reported p values are two-sided. P values < 0.05 were considered significant.

Contributions

Sophia Shimer was responsible for study conception and design, under the guidance of Kerin Adelson. Sophia Shimer wrote the protocol, surveys, and consent forms; completed the IRB submission; conducted recruitment and survey administration for the majority of study participants; and completed all data abstraction from medical records. Sophia Shimer and Maureen Canavan were responsible for data analysis and interpretation, with Maureen Canavan primarily providing guidance for kappa statistics and logistic regression models. Steven Gore provided expert advice on interpretation of leukemia-related clinical factors. Renee Capasso, Tehreem Babar, and Sara Tannenbaum assisted with recruitment and survey administration.

RESULTS

Participant characteristics

We enrolled 105 of 137 eligible patients (76.6% participation rate). We restricted our analysis to the 90 patient-physician pairs in which both parties completed a survey. Baseline patient characteristics are listed in **Table 1**. In terms of demographics, patients were predominantly white (77/90, 85.6%) and Christian (73/90, 81.1%). The median age was 59.5 years (range 22 to 86), and half the patients were female (45/90, 50.0%). In terms of clinical factors, most patients (73/90, 81.1%) had a diagnosis of AML, with the remainder having ALL. Patients at all stages of illness were represented: 41.1% were newly diagnosed, 31.1% were in remission, and 27.8% had relapsed or refractory disease. In addition, a third of patients (30/90, 33.3%) had either previously undergone

hematopoietic stem cell transplant or were admitted to undergo transplant at the time of enrollment.

Table 1: Baseline patient characteristics (n = 90)		
Characteristic	No.	%
Age: median (range), years	59.5 (22-86)	
Sex		
Male	45	50.0
Female	45	50.0
Race		
White	77	85.6
Non-white	13	14.4
Ethnicity		
Hispanic or Latino	8	8.9
Non-Hispanic or Latino	82	91.1
Type of leukemia		
AML	73	81.1
ALL	17	18.9
Disease status at enrollment		
New diagnosis	37	41.1
Remission	28	31.1
Relapse/refractory	25	27.8
Number of relapses		
0	58	64.4
≥ 1	32	35.6
Transplant status		
No HSCT	60	66.7
Current admission for HSCT	17	18.9
Past HSCT	13	14.4
Insurance		
Private	44	48.9
Medicare	33	36.7
Medicaid	13	14.4
Education (n = 88)		
≤ High school	22	25.0
Some college or trade school	27	30.7
≥ College degree	39	44.3
Income (n = 75)		
< \$19,999	9	12.0
\$20,000 - 79,999	28	37.3
\$80,000 -139,999	18	24.0
> \$140,000	20	26.7
Marital status		
Married or living with partner	53	58.9

Never married	15	16.7
Separated, divorced, or widowed	22	24.4
Religion		
Christian	73	81.1
Other	17	18.9
ECOG PS (n = 87)		
0	44	50.6
1 or 2	29	33.3
3 or 4	14	16.1
Abbreviations: AML, acute myeloid leukemia; ALL, acute lymphoblastic leukemia; HSCT, hematopoietic stem cell transplant; PS, performance status		

Patient perceptions of goals of care discussions

Most patients (71/85, 83.5%) wanted to be told their prognosis. Most patients (77/90, 85.6%) also wanted to be involved in treatment decision-making, although a minority (13/90, 14.4%) preferred to leave all treatment decisions up to their physicians. When asked to reflect on past conversations with their hematologist, only 56.8% (50/88) of patients recalled discussing chance of response to treatment, 28.1% (25/89) recalled discussing expected survival time, and 21.8% (19/87) recalled discussing end-of-life preferences.

Patient-physician comparisons

Patients were more optimistic than their physicians in assessing several different components of prognosis. When asked to describe their current health status at the time of enrollment, only 9.0% (8/89) of patients responded “terminally ill,” compared to 16.7% (15/90) of their physicians ($p = 0.03$; **Figure 1**).

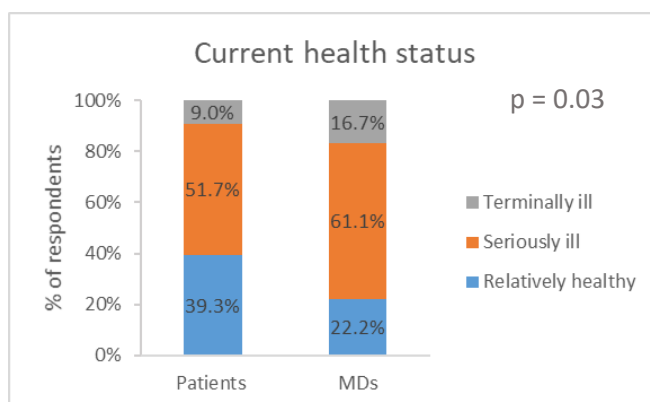


Figure 1. Patient vs physician perceptions of current health status.
Abbreviation: MDs, physicians.

When asked to select the primary goal of their current treatment, most patients (74/90, 82.2%) and physicians (71/90, 78.9%) shared a goal of cure (**Figure 2**). However, they differed significantly in their perceptions of the likelihood of cure. The majority of patients (45/88, 51.1%) thought their chance of cure was > 80%, compared to only a small minority (3/90, 3.3%) of physicians ($p < 0.001$; **Figure 3**). **Table 2** shows a cross-tabulation of paired patient-physician responses estimating chance of cure, illustrating how few pairs gave matching responses. Kappa statistics confirmed that patient-physician concordance regarding chance of cure was poor ($\kappa = 0.05$; 95% CI, -0.02 to 0.13).

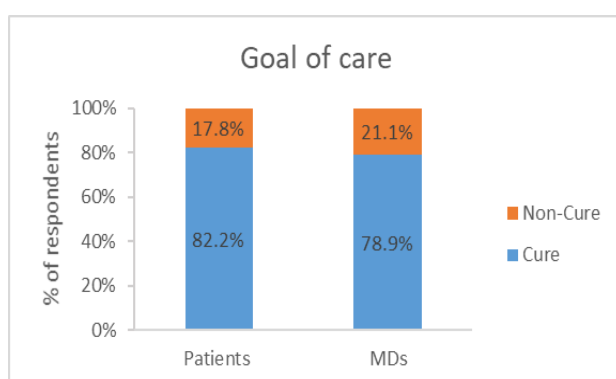


Figure 2. Patient vs physician perceptions of primary goal of care.

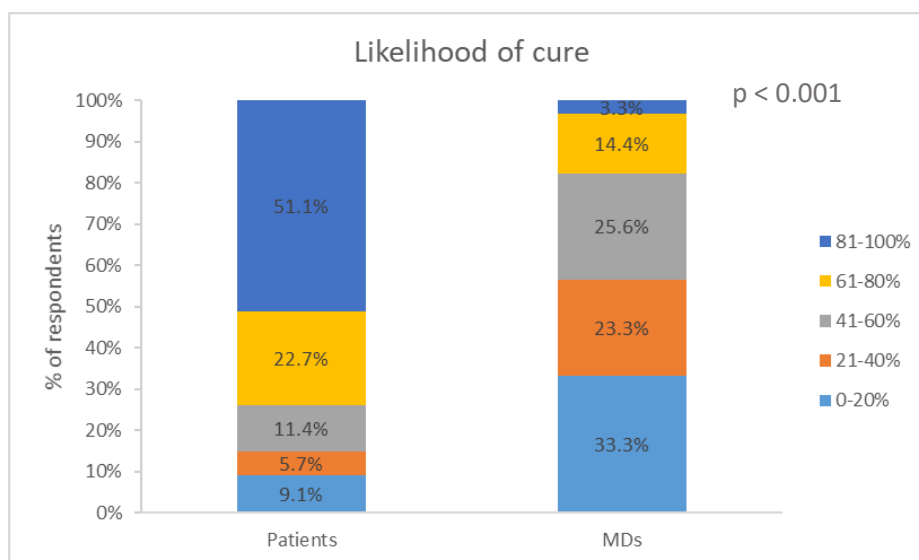


Figure 3. Patient vs physician perceptions of the likelihood of cure. Patients at all stages of illness (relapsed and non-relapsed) are included.

Table 2: Patient-physician concordance regarding chance of cure (n = 88 pairs)^A

	Physician response					
Patient response	0-20%	21-40%	41-60%	61-80%	81-100%	Total
0-20%	5	2	0	1	0	8
21-40%	2	1	1	1	0	5
41-60%	5	2	2	1	0	10
61-80%	9	3	4	4	0	20
81-100%	8	13	15	6	3	45
Total	29	21	22	13	3	88
κ coefficient (95% CI)	0.05 (-0.02 to 0.13)					
^ This table shows a cross-tabulation of paired patient-physician responses estimating chance of cure.						

Patients estimated chance of cure more optimistically than their physicians at all stages of illness. This became apparent when patients were stratified by relapse status (**Table 3**). In the non-relapsed group, 57.9% (33/57) of patients vs only 5.2% (3/58) of their physicians reported a > 80% chance of cure ($p < 0.001$). In the relapsed group, 38.7%

(12/31) of patients vs 0.0% (0/32) of their physicians reported a >80% chance of cure ($p < 0.001$).

Table 3: Patient vs physician perceptions of chance of cure, stratified by relapse status

	Non-relapsed (n = 58)			Relapsed (n = 32)		
Chance of cure (%)	Patients (%)	Physicians (%)	p-value	Patients (%)	Physicians (%)	p-value
0-20	5.3	19.0	< 0.001	16.1	59.4	< 0.001
21-40	3.5	22.4		9.7	25.0	
41-60	12.3	32.8		9.7	12.5	
61-80	21.1	20.7		25.8	3.1	
81-100	57.9	5.2		38.7	0.0	

Patients were also more optimistic than their physicians about the likelihood that treatment would extend their life (**Figure 4**) and the likelihood that treatment would lessen their suffering (**Figure 5**). Only 41.1% (37/90) of surveyed patients were willing to estimate how much longer they had to live; the rest responded “don’t know,” “in God’s hands/up to fate,” or left the question blank. Among those willing to provide an estimate, 75.7% (28/37) of patients vs 28.4% (21/74) of physicians estimated a survival time of > 5 years ($p < 0.001$; **Figure 6**). Patient-physician concordance was poor for chance of extending life ($\kappa = 0.08$; 95% CI, -0.04 to 0.20), chance of lessening suffering ($\kappa = 0.02$; 95% CI, -0.08 to 0.12), and estimated survival time ($\kappa = 0.08$; 95% CI, -0.08 to 0.24).

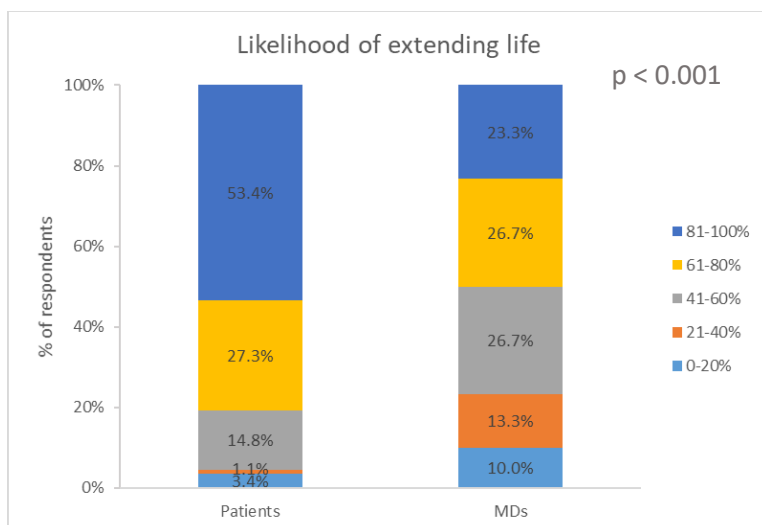


Figure 4. Patient vs physician perceptions of the likelihood that treatment will extend life.

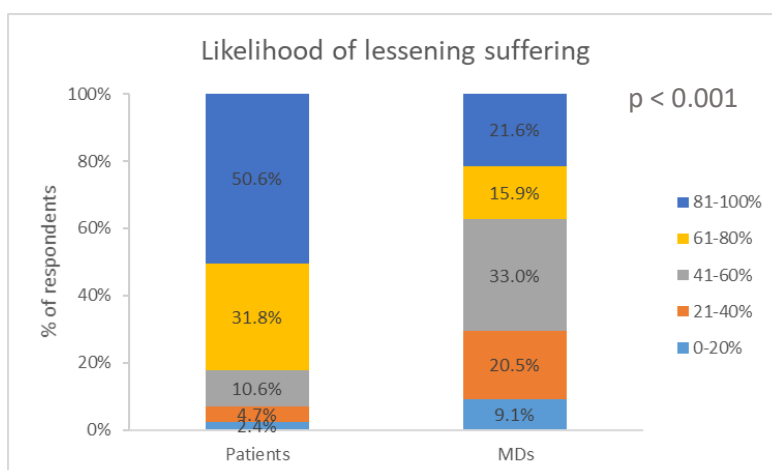


Figure 5. Patient vs physician perceptions of the likelihood that treatment will lessen suffering.

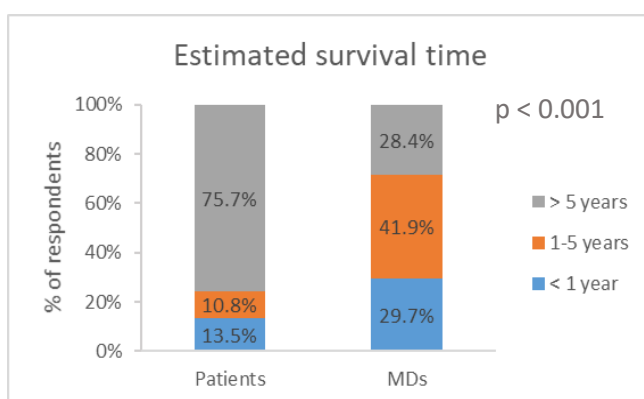


Figure 6. Patient vs physician estimates of survival time.

Exploratory analyses of associations between prognostic concordance and other covariates

We conducted an exploratory analysis with the goal of identifying demographic and clinical factors associated with patient-physician prognostic concordance. However, no associations emerged as significant in our bivariate or multivariable models. Specifically, there were no associations between prognostic concordance and age, sex, race, insurance type, education, religion, ECOG performance status, or relapse status. Prognostic concordance was also not significantly associated with health-related quality of life as measured by FACT-Leu.

Comparison of estimated vs actual survival time

By the end of the follow-up period, 53.3% (48/90) of patients in the cohort had died. The median overall survival of the entire cohort was 18 months (95% CI, 13 to 30 months). **Figure 7** shows Kaplan-Meier survival plots stratified by relapse status; non-relapsed patients lived significantly longer than relapsed patients (median survival, 23 months vs 7 months, $p = 0.002$).

For participants who had been willing to estimate survival time on the baseline survey ($n = 37$ patients and $n = 74$ physicians), we compared estimated vs actual survival (**Figure 8**). Only 8.1% (3/37) of patients and 14.9% (11/74) of physicians provided an accurate estimate (actual survival was within the time range estimated). Both patients and physicians were more likely to overestimate than underestimate survival, but patients

were especially optimistic: 54.1% (20/37) of patients vs 33.8% (25/74) of physicians overestimated, and 5.4% (2/37) of patients vs 12.2% (9/74) of physicians underestimated ($p < 0.001$).

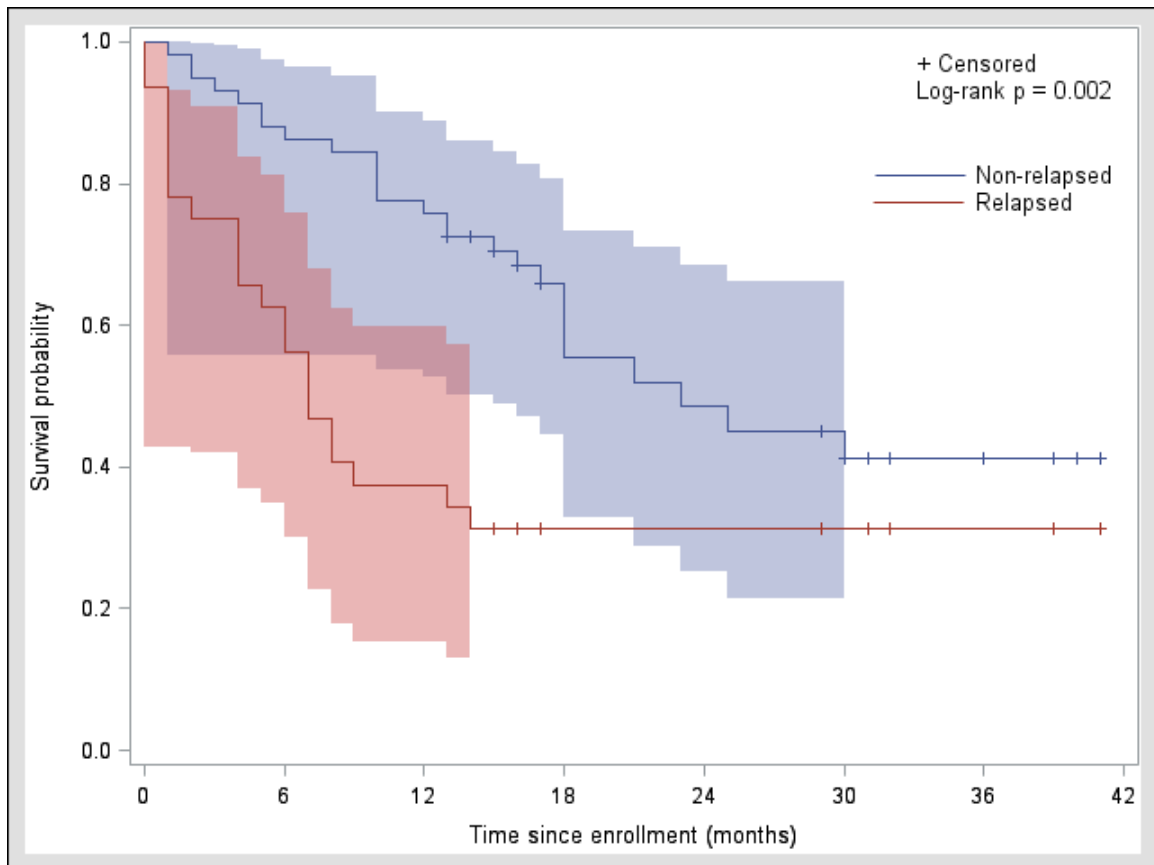


Figure 7: Overall survival stratified by relapse status at the time of enrollment. Shaded areas represent Hall-Wellner 95% confidence bands.

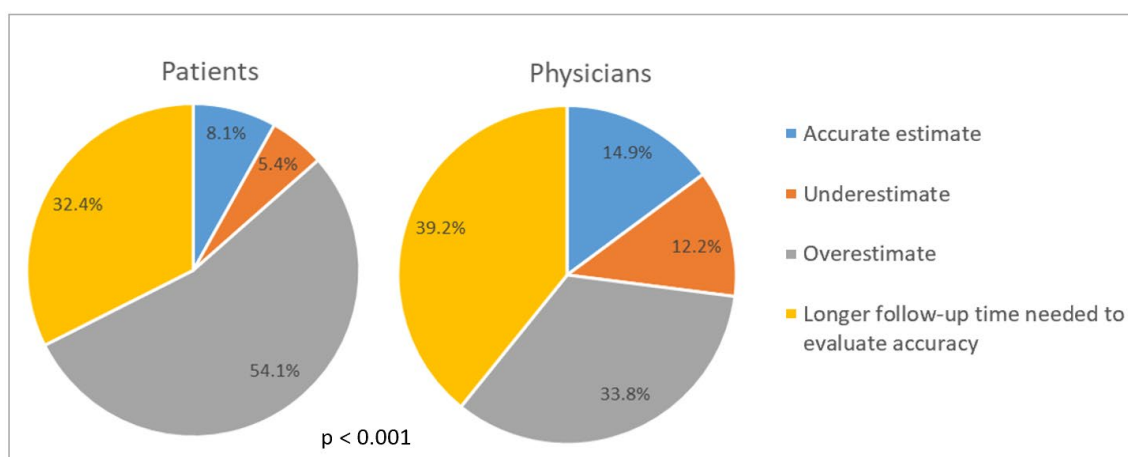


Figure 8: Accuracy of patients' and physicians' survival time estimates, as compared to actual survival. "Longer follow-up time needed to evaluate accuracy" means that the patient was still alive at the end of the follow-up period but had not yet attained the estimated survival time.

Healthcare utilization at the end of life

Table 4 shows healthcare utilization at the end of life for the 48 patients who died during follow-up. Half of these patients (24/48, 50.0%) died in the hospital as opposed to at home or in hospice. Although 47.9% (23/48) of those who died received hospice services, transition to hospice usually only occurred when death was imminent: only 10.4% (5/48) enrolled in hospice more than 7 days before dying. Within 30 days of death, 93.8% (45/48) of patients were hospitalized, 54.2% (26/48) were admitted to the ICU, 33.3% (16/48) were intubated, and 10.4% (5/48) received CPR. Within 14 days of death, 41.7% (20/48) of patients received chemotherapy or targeted therapy. Within 7 days of death, 66.7% (32/48) of patients received a red blood cell or platelet transfusion. The majority (31/48, 64.6%) of patients who died received a palliative care consultation.

Table 4: Healthcare utilization at the end of life (n = 48 patients)		
Characteristic	No. of patients	%
Place of death		
Hospital	24	50.0
Hospice (home services or inpatient facility)	23	47.9
Home without hospice	1	2.1
Hospice enrollment		
> 7 days before death	5	10.4
≤ 7 days before death	18	37.5
Hospitalization within 30 days of death	45	93.8
ICU admission within 30 days of death	26	54.2
CPR within 30 days of death	4	8.3
Intubation within 30 days of death	16	33.3
Chemotherapy or targeted therapy within 14 days of death	20	41.7
Transfusion within 7 days of death	32	66.7
Received palliative care consult	31	64.6%
Abbreviations: ICU, intensive care unit; ED, emergency department; CPR, cardiopulmonary resuscitation		

DISCUSSION

Several key findings emerged from this study of prognostic understanding and end-of-life outcomes in the acute leukemia population. First, more patients wanted to know their prognosis than recalled discussing it with their hematologist, indicating a gap between patients' desire for and receipt of prognostic information. Second, we found substantial discrepancies between patient and hematologist perceptions of prognosis. Patients tended to be more optimistic: they were less likely to label themselves terminally ill, more likely to perceive a high chance of cure, and more likely to estimate a survival time of > 5 years. Third, both patients and physicians overestimated survival, with patients being especially optimistic. Fourth, healthcare utilization at the end of life was high.

Our finding of a large patient-physician discrepancy in perceived chance of cure is in line with other recent studies in the hematologic malignancy population.^{10,14} In our study's acute leukemia population, 51.1% of patients vs 3.3% of physicians thought their chance of cure was > 80%; similarly, in a recent study of older adults with AML, El-Jawahri et al. reported that 52% of patients vs 0% of physicians thought their chance of cure was > 75%.¹⁴

One unique aspect of our study was that we assessed multiple dimensions of prognostic understanding, asking not only about chance of cure but also about current health status, goals of care, estimated survival time, and likelihood that treatment would extend life or lessen suffering. Perceptions of anticipated suffering have been particularly overlooked in previous research. In our study, patients were more likely than their physicians to think that the treatment they were receiving would reduce their suffering. This discrepancy suggests that patients may be minimizing the risk of side effects and overestimating how treatment would alleviate their symptom burden. In fact, physical and psychosocial symptom burdens often increase during active treatment.^{27,35} Misperceptions about anticipated suffering are especially important to recognize in patients for whom goals of care have shifted from extending life toward preserving quality of life.

In our study, the gap between patient and physician understanding was most striking in the relapsed group. Over a third of relapsed patients vs none of their physicians

thought chance of cure was > 80%. Inaccurate prognostic perceptions likely have a greater impact on treatment decisions in the relapsed population—especially in relapsed patients who are also older and frail. Young, relatively fit patients with newly diagnosed leukemia would likely choose the same treatment—intensive induction chemotherapy—whether they inaccurately believed their chance of cure to be > 80% or accurately understood it to be 30-40%. On the other hand, for older, medically frail patients with relapsed disease deciding whether to pursue further lines of cure-directed therapy, the difference between inaccurately believing chance of cure to be > 80% and accurately understanding it to be < 10% could be quite consequential. Unrealistic expectations may predispose vulnerable patients toward overly aggressive and perhaps futile treatment. Thus, the high rate of prognostic overestimation among relapsed patients is particularly concerning.

Our findings raise the question of whether oncologists in clinical practice should be aiming for perfect patient-physician agreement on prognosis. Is patients' relative optimism always problematic? Optimism can be part of a constructive coping strategy, and may help patients persevere through prolonged, socially isolating hospitalizations and intensive, high-toxicity treatments.³⁶ Oncologists often worry that disclosing a poor prognosis will take away hope or otherwise cause psychological harm.^{20,37} We did not find any significant association between prognostic understanding and quality of life, including emotional well-being, but we did not specifically ask about loss of hope.

The existing literature on this topic has yielded mixed results. In a study on the psychological impact of acute leukemia, Gheihman et al. found that while depression was common and related to physical symptom burden, hopelessness was less common and associated with older age and lower self-esteem. Perceived poor communication with healthcare providers was not independently associated with hopelessness.¹⁶ In the Coping with Cancer study, prognostic disclosures were not associated with emotional distress or harm to the patient-physician relationship.¹ However, in another study of patients with advanced gastrointestinal cancer, accurate prognostic understanding was associated with worse quality of life and anxiety.³⁸ Finally, in the hematologic malignancy population, El-Jawahri and colleagues reported that more accurate prognostic understanding was associated with worse quality of life and increased depression.^{10,14} Given the lack of consensus, a cautious approach to prognostic disclosure is warranted. In their conversations with patients, oncologists must balance maintaining hope with the need to set realistic expectations to enable informed decision-making.

The intensity of healthcare utilization at the end of life in our cohort matched or exceeded that found in previous studies in the hematologic malignancy population.^{22,24,25} In our cohort, within the last month of life almost all patients were hospitalized, over half were admitted to the ICU, and many received chemotherapy. While we observed a relatively high rate of hospice utilization (47.9%), enrollment was usually late, occurring just days before death. Several factors may contribute to this

pattern. On the one hand, it may reflect a sudden deterioration in clinical status and transition to end-of-life care. Alternatively, it may point toward barriers to timely hospice enrollment such as a lack of blood product transfusion services. In a study of Medicare beneficiaries with leukemia, transfusion dependence was associated with higher rates of hospice utilization but shorter lengths of stay.³⁹ Indeed, in our cohort the majority of patients (66.7%) received a transfusion within a week of death; perhaps some deferred hospice enrollment because they would be unable to receive supportive transfusions. This highlights the need for hospice services that allow transfusions as a component of comfort care.

Interestingly, in our cohort we also observed a higher rate of utilization of palliative care services compared to previous reports. In our sample, the majority (64.6%) of patients who died received a palliative care consult, compared to only 16.2% of a cohort of older adults with AML and 33% of patients in a heterogeneous cohort of hematologic malignancy patients, both at academic institutions.^{22,24} These variable rates may reflect institution-level differences in patterns of palliative care referral.

Our study has several limitations. First, the cross-sectional design of our survey did not allow for tracking changes in prognostic understanding over time. A longitudinal study with surveys at different time points would be better suited for identifying clinical events along the disease trajectory that trigger changes in understanding. Second, our small sample size consisting of predominantly white patients limited our ability to detect

associations between demographic and clinical variables and prognostic understanding in our exploratory analyses. Previous studies in solid tumor populations have found that patients who are nonwhite, older, or non-native English speakers are more likely to report a prognosis or treatment intent that is discordant from their physician's.^{7,32} Third, we did not assess whether patients knew that their hematologist's opinion differed from their own; in other words, we did not distinguish between known and unknown discordance. Gramling et al. found that unknown discordance was more common in the advanced cancer population and posited that it is a marker of poor patient-provider communication.³² Fourth, in our analysis of healthcare utilization, we did not distinguish between chemotherapy given with curative vs palliative intent, which limited our ability to assess the appropriateness of high rates of chemotherapy administration near death.

Finally, this study did not directly evaluate patient-physician communication. Thus, the actual prognostic discussion remains a "black box," and we are not able to determine the exact locus of the discrepancy in patient-physician perceptions. Are physicians not disclosing the prognosis, or are patients simply not hearing it, perhaps because they are too overwhelmed to listen? Future work will include audio recordings of prognostic discussions to crack open this "black box."

In summary, this observational study of prognostic understanding in the acute leukemia population revealed that most patients strikingly overestimate their prognosis

compared to their hematologist's assessment and to actual end-of-life outcomes. This study went beyond previous work by assessing more dimensions of prognostic understanding and comparing patients at different stages of illness. Our findings are significant because, while optimism can help with coping, there is also a risk of unrealistic expectations influencing treatment decisions, especially after relapse. Future work will focus on two areas: 1) examining actual patient-physician prognostic conversations and 2) further exploring associations between prognostic understanding and patterns of care.

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APPENDIX

Appendix 1: Patient Survey

STUDY ID #: _____

Assessment of Prognostic Understanding and Perceived Goals of Care in Patients with Leukemia

PATIENT SURVEY

Please circle your answers.

A: THE BRIEF ILLNESS PERCEPTION QUESTIONNAIRE (B-IPQ)

For the following questions, please circle the number that best corresponds to your views now.

1. How much does your illness affect your life?	0 No effect at all	1	2	3	4	5	6	7	8	9	10 Severely affects my life
2. How long do you think your illness will continue?	0 A very short time	1	2	3	4	5	6	7	8	9	10 For the rest of my life
3. How much control do you feel you have over your illness?	0 Absolutely no control	1	2	3	4	5	6	7	8	9	10 Extreme amount of control
4. How much do you think your treatment can help your illness?	0 Not at all	1	2	3	4	5	6	7	8	9	10 Extremely helpful
5. How much do you experience symptoms from your illness?	0 No symptoms at all	1	2	3	4	5	6	7	8	9	10 Many severe symptoms
6. How concerned are you about your illness?	0 Not at all concerned	1	2	3	4	5	6	7	8	9	10 Extremely concerned
7. How well do you feel you understand your illness?	0 Don't understand at all	1	2	3	4	5	6	7	8	9	10 Understand very clearly
8. How much does your illness affect you emotionally? (e.g., does it make	0 Not at all affected emotionally	1	2	3	4	5	6	7	8	9	10 Extremely affected emotionally

you angry, scared, upset or depressed?)										
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B: CONTROL PREFERENCES SCALE (CPS)

1. In terms of making decisions about your health care with your doctor, which ONE of the following best describes how you would like to make these decisions?
 - (1) Make the final selection about which treatment I will receive
 - (2) Make the final selection after seriously considering my doctor's opinion
 - (3) Have my doctor and I share responsibility for deciding what treatment is best
 - (4) Have my doctor make the final decision but consider my opinion
 - (5) Leave all decisions regarding treatment to my doctor

C: UNDERSTANDING OF PROGNOSIS

1. How would you describe your current health status?
 - (1) Relatively healthy
 - (2) Seriously ill but not terminally ill
 - (3) Seriously and terminally ill
2. Did your cancer doctor discuss how long you may have to live?
 - (1) Yes
 - (2) No
3. If your doctor knew how long you had left to live, would you want him or her to tell you?
 - (1) Yes
 - (2) No
4. Based on your understanding about what your doctors have told you about your cancer, your health in general, and the treatments you are receiving, how long do you think you have to live?
 - (1) Up to 3 months
 - (2) 3 to 6 months
 - (3) 6 to 12 months
 - (4) 1-2 years
 - (5) 2-5 years
 - (6) At least 5 years
 - (7) In God's hands/Up to fate
 - (8) Don't know
5. What is the basis of this estimate of how long you have to live?
 - (1) My cancer doctor told me
 - (2) A palliative care specialist told me
 - (3) Other clinic staff told me
 - (4) My personal belief, having to do with religion
 - (5) My personal belief, not having to do with religion
 - (6) Other (SPECIFY): _____

D: PERCEPTION OF GOALS OF CARE AND TREATMENT PREFERENCES

1. Did your cancer doctor talk to you about your goals of care? A goals of care conversation includes discussions about the likely outcome of your illness, possible treatment options, and clarifies things that are most important to you given your cancer diagnosis.
 - (1) Yes
 - (2) No
2. What is the primary goal of your current medical treatment?
 - (1) To cure my cancer
 - (2) To extend my life as long as possible without cure
 - (3) To lessen suffering as much as possible
3. How likely do you think you are to be cured of cancer?
 - (1) Very likely
 - (2) Likely
 - (3) Unlikely
 - (4) Very unlikely
4. If you had to estimate your chance of being cured of cancer, what would it be?
 - (1) 0%
 - (2) 1% to 20%
 - (3) 21% to 40%
 - (4) 41% to 60%
 - (5) 61% to 80%
 - (6) 81% to 100%
5. How likely do think it is that your current treatment will extend your life?
 - (1) Very likely
 - (2) Likely
 - (3) Unlikely
 - (4) Very unlikely
6. If you had to estimate the chance that your current treatment will extend your life, what would it be?
 - (1) 0%
 - (2) 1% to 20%
 - (3) 21% to 40%
 - (4) 41% to 60%
 - (5) 61% to 80%
 - (6) 81% to 100%
7. How likely do you think it is that your current treatment will lessen your suffering?
 - (1) Very likely
 - (2) Likely

- (3) Unlikely
- (4) Very unlikely

8. If you had to estimate the chance that your current treatment will lessen your suffering, what would it be?
 - (1) 0%
 - (2) 1% to 20%
 - (3) 21% to 40%
 - (4) 41% to 60%
 - (5) 61% to 80%
 - (6) 81% to 100%
9. Did your cancer doctor discuss specific numbers about your chance of responding to your current treatment?
 - (1) Yes
 - (2) No
10. Did your cancer doctor talk to you about medications or treatments that could help with the side effects of your cancer treatments or help with the side effects of the cancer itself?
 - (1) Yes
 - (2) No
11. Did your cancer doctor talk to you about your preferences for cancer treatment?
 - (1) Yes
 - (2) No
12. Overall, do you agree that the treatments you've gotten for your cancer match your preferences?
 - (1) Strongly Disagree
 - (2) Disagree
 - (3) Neither agree nor disagree
 - (4) Agree
 - (5) Strongly agree
13. What is more important to you: treatment that focuses on quality of life or treatment that focuses on lengthening life?
 - (1) Focus on quality of life
 - (2) Focus on lengthening life
14. If a therapy that lengthened your life resulted in a worse quality of life, would you still choose it?
 - (1) Yes
 - (2) No
 - (3) Don't know
15. Do you think your doctor would offer you treatment that would not help you just because he or she thought you wanted it?

- (1) Yes
- (2) No

16. Do you think your doctor would offer you treatment that would not help you but would help others with the information its effect on you would provide?

- (1) Yes
- (2) No

17. Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?

- (1) Yes
- (2) No

18. Do you have a signed Living Will or Durable Power of Attorney for health care, both, or neither?

- (1) Yes, Living Will
- (2) Yes, Durable Power of Attorney
- (3) Yes, both
- (4) Neither
- (5) Don't know

19. Have you completed a Do Not Resuscitate (DNR) order?

- (1) Yes
- (2) No
- (3) Don't know

20. Do you think it would be a bad thing for a person to die in the ICU versus elsewhere (e.g. home, hospital, hospice)?

- (1) Yes
- (2) No

21. Would you want the doctors here to do everything possible to keep you alive even if you were going to die in a few days anyway?

- (1) Yes
- (2) No

E: RELIGIOUSNESS

1. What is your religious preference?

- (1) Agnostic
- (2) Atheist
- (3) Buddhist
- (4) Catholic
- (5) Christian
- (6) Hindu
- (7) Jewish
- (8) Muslim
- (9) Protestant

(10) Other (SPECIFY): _____

2. How religious/spiritual do you consider yourself to be?
 - (1) Not at all
 - (2) A little
 - (3) Somewhat
 - (4) Very
 - (5) I don't know
3. To what extent do your religious beliefs or activities help you cope with or handle your illness?
 - (1) Not at all
 - (2) To a small extent
 - (3) To a moderate extent
 - (4) To a large extent
 - (5) It is the most important thing that keeps me going
 - (6) Don't know

F: DEMOGRAPHICS

1. How old are you? _____ years old
2. What is your gender?
 - (1) Male
 - (2) Female
 - (3) Other (SPECIFY): _____
3. Are you now married, living with a partner in a marriage-like relationship, widowed, divorced, separated, or never married?
 - (1) Married
 - (2) Living with partner
 - (3) Widowed
 - (4) Divorced
 - (5) Separated
 - (6) Never married
4. Do you have health insurance now? (If NO, skip to question 6)
 - (1) Yes
 - (2) No
5. What type of health insurance coverage do you currently have?
 - (1) Private health insurance or HMO
 - (2) Medicare
 - (3) Medicaid
 - (4) Veteran's administration (VA) health care
 - (5) Other government health plan
 - (6) Other non-government health plan
 - (7) Don't know

6. What is the highest grade of school you have completed?
 - (1) Never attended/Kindergarten only
 - (2) Less than Junior High school (grades 1-8)
 - (3) Less than High School (grades 8-11)
 - (4) High School graduate or GED
 - (5) Some college, no degree
 - (6) Trade/Vocational school
 - (7) College degree
 - (8) Graduate School
7. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?
 - (1) Never
 - (2) Rarely
 - (3) Sometimes
 - (4) Often
8. Are you Hispanic or Latino?
 - a. Yes
 - b. No
9. What is your race?
 - a. White
 - b. Black or African American
 - c. Asian
 - d. American Indian/Alaskan Native
 - e. Native Hawaiian/Pacific Islander
 - f. More than one race (SPECIFY): _____
 - g. Other (SPECIFY): _____
10. Which of the following categories best describes the total amount of money that came into your household last year before taxes?
 - a. \$ 0-19,999
 - b. \$ 20,000-39,999
 - c. \$ 40,000-59,999
 - d. \$ 60,000-79,999
 - e. \$ 80,000-99,999
 - f. \$ 100,000-119,000
 - g. \$ 120,000-139,000
 - h. \$ 140,000 and over
 - i. Don't know

Appendix 2: Physician Survey

Study ID #: _____

Physician Assessment of Prognosis and Primary Goal of Care**Please circle your answers.**

1. How would you describe this patient's current health status?
 - (1) Relatively healthy
 - (2) Seriously ill but not terminally ill
 - (3) Seriously and terminally ill

2. How long do you think this patient has to live?
 - (1) Up to 3 months
 - (2) 3 to 6 months
 - (3) 6 to 12 months
 - (4) 1-2 years
 - (5) 2-5 years
 - (6) At least 5 years
 - (7) In God's hands/Up to fate
 - (8) Don't know

3. What is the primary goal of this patient's current medical treatment?
 - (1) To cure the cancer
 - (2) To extend life as long as possible without cure
 - (3) To lessen suffering as much as possible

4. How likely do you think this patient is to be cured of cancer?
 - (1) Very likely
 - (2) Likely
 - (3) Unlikely
 - (4) Very unlikely

5. Please estimate the chance that this patient will be cured of cancer.
 - (1) 0%
 - (2) 1% to 20%
 - (3) 21% to 40%
 - (4) 41% to 60%
 - (5) 61% to 80%
 - (6) 81% to 100%

6. How likely do think it is that this patient's current treatment will extend his or her life?
 - (1) Very likely
 - (2) Likely
 - (3) Unlikely
 - (4) Very unlikely

7. Please estimate the chance that this patient's current treatment will extend his or her

life.

- (1) 0%
- (2) 1% to 20%
- (3) 21% to 40%
- (4) 41% to 60%
- (5) 61% to 80%
- (6) 81% to 100%

8. How likely do you think it is that this patient's current treatment will lessen his or her suffering?

- (1) Very likely
- (2) Likely
- (3) Unlikely
- (4) Very unlikely

9. Please estimate the chance that this patient's current treatment will lessen his or her suffering.

- (1) 0%
- (2) 1% to 20%
- (3) 21% to 40%
- (4) 41% to 60%
- (5) 61% to 80%